



Breaking Ground

'The Biggest Part of the Job Is Being an Advocate'

By Jim Summerville

Susan King, a young woman with mental retardation, knew what she wanted in her life, starting with a good job. Her friend and companion Marie Turnmyre saw plainly that Susan would be a conscientious employee. But Susan could get no support from her agency, Marie's employer.

It was a hard place for both of them. "This is what I want to do," Susan pleaded. "I don't see why I can't." For her part, Marie said, "I know how to fix it, but I work for the agency. How can I help, since I'm not the job coach or the employment coordinator?"

In the end, Susan and Marie made a crucial choice with the goal of improving Susan's life.

"I left for a new agency," says Marie, "and Susan came with me. It meant a pay cut—and I was called 'disloyal'—but I decided people are my first loyalty."

Susan now has supported employment at the Kroger store two miles from her home, where she has received company recognition for doing a good job. She also does volunteer work at a day care agency. On her days off, she can take advantage of her new agency's outings, such as those to Nashville Shores.

Marie, who serves as chair of the Direct Support Professionals Association of Tennessee (DSPAT), took a lesson out of this experience.

"Yes, we in this work have to master many things: cooking, budgeting, and the like. But the biggest part of the job is being an advocate.

"We like to think that agencies are totally fair and committed to the support of the individuals with disabilities that they are supposed to serve. But I've learned not to assume this."

She cites the poignant example of one of Susan's former roommates, Jennifer, who has mental retardation. "She was high functioning," Marie recalls.

Marie (left) and Susan

continued on the next page



IN THIS ISSUE

Disability
Mega-Conference
See Page 2

Senior Caregivers
Get Support
See Page 5

Direct Support
Professionals
Recognized
See Page 8

Governor Names 14
to the Council
See Page 12

Partner's Annual
Reunion
See Page 16

Get Set for
Youth Leadership
Forum 2003!
See Page 17

Disability "Mega-Conference" Slated for Next Summer

2

More than fifteen statewide, regional, and local disability groups have joined together to plan a mega-conference on disability issues and most promising practices next summer. The conference will take place on June 19-22, 2003, at the Cool Springs Marriott Hotel in Franklin, Tennessee.

The conference will cover areas of interest to all disabilities and will span all areas of community life. Work groups have been formed to tackle the program agenda, presenters, exhibits, special conference events, accommodations,

publicity and other conference areas.

To join in on conference planning activities, call Walter Rogers at The Arc of Tennessee (615-248-5878) or Ruthie Beckwith at the Tennessee Microboards Association (615-898-0300). The conference has a Yahoo group listserv and is developing a website that should be up and running by January.

Please consider joining one or more planning groups. By doing so your organization will be listed as a sponsor, and the agenda will be sure to include topics of interest to your members. Let us hear from you! ■

The Biggest Part of the Job Is Being an Advocate *continued from page 1*

"But when the agency placed her with us, it was suddenly a confusing, unfamiliar environment. The agency should have been more selective and cautious."

The difficulties mounted until Jennifer turned violent and threatened Susan, forcing her to barricade herself in her room.

Ultimately, Susan was able to find a new, safe residence with Marie, and another roommate Cynthia, to whom Ms. Turnmyre is also companion. Ms. Turnmyre says, "I have a sense of failure with Jennifer. What if I'd done this? What if I'd done that? But my background was business, and I didn't know much about serious behaviors. There was harm done all around since Jennifer had to be hospitalized—which better knowledge and understanding might have prevented."

Ms. Turnmyre believes that, once organized, direct support professionals can insist that agencies do more than merely meet the letter of State regulations when it comes

to matching individuals and companions.

Ms. Turnmyre also hopes to see DSPAT increase the appreciation of the work of direct support professionals among the public at large. "We offer a wealth of knowledge that's not being utilized," she observes. She acknowledges that the image of the profession is not strong.

"We have to begin to change that by changing our own view of ourselves," she insists. She hopes to see more and better training available for direct support professionals—and rewards commensurate with that. "What if we can obtain better, different, more exciting, job-specific training?" she wonders. "And what about credentialing, so that there's a correlation between the training you have and the salary you receive?"

Ms. Turnmyre is encouraged by DSPAT's initial reception. "State regulators and rule-makers seem open to our input," she says. "In the past, we just haven't been offering to talk."

DSPAT's next step is to enlist more of the rank-and-file support professionals into membership and participation in common cause for a better future. "Don't settle for what you have—that's our message," says Ms. Turnmyre. ■

Jim Summerville

is editor of

Breaking Ground.

Overcoming Isolation, Raising Standards Among Goals of New Group

By Jim Summerville

Low wages, high turnover, and minimal training have been persistent problems for persons who provide friendship, counseling, and care to people with developmental disabilities. To address these and related issues, leaders in the field have begun a new organization, the Direct Support Professionals of Tennessee (DSPAT).

Who they are. A direct support professional is one who works directly with individuals with a disability, assisting them in many activities of daily living, from meal preparation to transportation to managing a household budget. There are more than 4,000 of these professionals in Tennessee, working at supported and assisted living agencies, day service programs, job training programs, or self-employed.

Many persons enter the field with little or no preparation or even orientation. Expectations by both the agency and the individual with the disability often surprise the new caregiver. That fact, coupled with pay that may not be commensurate with the responsibility, can cause a support provider to quickly become disillusioned and to leave. Adding to the burdens of the task, State regulation over the field has been growing in depth and complexity in recent years.

Getting organized. The idea for a statewide organization of direct support professionals that would address some of these problems arose about two years ago. Richard Smith, then with the State's Division of Mental Retardation Services, remarked to a gathering of providers: "You are the largest body of employees in the field of developmental disabilities—but you're the lowest paid." This seed took some time to germinate, but in March 2002, Don Haughton and Marie Turnmyre, themselves support professionals, invited directors of 183 agencies involved in supported and assisted living to a meeting. That gathering became the beginning of DSPAT.

"We are an association of people who want to pull ourselves up by our bootstraps," says Sam Adams, vice chair of the group.

Mr. Adams expects the group to address the issue of low wages, once the organization has gained strength in numbers. He cites the success of the Direct Support Professionals of Missouri, which in its first year of operation won a blanket increase in the hourly pay for the membership.

Another of DSPAT's goals is to strengthen State laws to require training of persons entering the direct service profession.

An isolated group. DSPAT also hopes to improve statewide communication among direct support employees. "I can't think of a more isolated group of people," Mr. Adams remarked. DSPAT hopes to overcome this isolation through a newsletter, monthly meetings, and a series of workshops around the state.

A related goal of DSPAT is to develop and to strengthen working relationships between direct support professionals, consumers and their families, and state and federal funding and regulatory organizations. For example, DSPAT would like to see a better understanding of the day-to-day working conditions that support providers face.

DSPAT meets on the second Wednesday of each month at 1161 Murfreesboro Road, 1st floor conference room, Nashville. Refreshments are served at 9:30 a.m., and the business meeting takes place from 10-11 a.m. Voting membership in DSPAT is open to anyone who works directly with consumers, giving direct support for at least 30 hours a month. ■

For more information contact:

Mr. Sam Adams, DSPAT

1161 Murfreesboro Road, Suite 215

Nashville, Tennessee 37217

Phone: (615) 847-8615 Fax: (615) 399-8407

Website: directsupportprofessionals@juno.com

Getting On the Bus in Chattanooga

By Errol Elshtain

4

In 1998, the Council on Developmental Disabilities funded a one-year project with the Chattanooga Area Regional Transportation Authority (CARTA) to change the perceptions and habits of both transit drivers and individuals with disabilities. CARTA had realized that their transit drivers did not know how best to greet and assist riders with disabilities. As a result, many individuals with disabilities who could ride fixed-route buses did not. Instead, they continued to use paratransit Care-A-Van vehicles, which are more expensive to operate.

CARTA, in collaboration with Siskin Rehabilitation Center, developed a training program and video for the transit drivers. Through this training and exposure to individuals with disabilities, a mutual understanding between drivers and riders was established. CARTA's vision was that individuals with transportation issues have transit alternatives that increase their independence and inclusion, ranging from reservation-based Care-A-Van, to fixed-route transit, to combinations thereof.

The outcomes of the project included

- improved mobility choices for individuals with disabilities
- decreased cost of transportation for individuals with disabilities
- increased amount of transportation available to individuals with disabilities
- enhanced quality of transportation for individuals with disabilities
- integration and inclusion of individuals with disabilities into general public transportation

*Errol Elshtain is
planning coordinator
at the Tennessee
Council on
Developmental
Disabilities.*



Learning how to secure wheelchairs and operate lifts has become part of bus drivers' training, thanks to a Council grant.

CARTA has continued training drivers and riders through "Raising Individuals with Disabilities Empowerment Project (Project RIDE)." This has resulted in the convenience of being able to travel as desired, versus having to schedule in advance, coupled with the reduced cost of riding buses versus paratransit vehicles. Moreover, riders with disabilities can count on a well-trained, customer-oriented fleet of drivers.

Again collaborating with Siskin Rehabilitation Center, CARTA is now proceeding with a new grant from the Council. This grant is to prepare a program to present the training developed for the CARTA transit drivers to other transportation systems in Tennessee. The concept is to interest as many as five other systems in the State to undertake the training program. ■

For more information contact:
Dana Wilson, Travel Trainer
Siskin Rehabilitation Center
Phone: (423) 634-1576



No longer "going it alone," seniors who care for a family member with a disability get advice and support.



5

Older Caregivers Project Gets Underway

By Wanda Willis

The Tennessee Older Caregivers Project has taken off in Chattanooga with two major events. The Project, headed by Team Evaluation Center, Inc., is focused on identifying models of assistance for caregivers, 65 years and older, who provide primary assistance for a family member with a disability in their home. The Project receives funding from the Tennessee Council on Developmental Disabilities and the National Council on Aging in Washington, D.C. June Phillips, executive director of Team Evaluation, and Alan Bullard, consultant, provide staff support.

On October 8, 2002, a reception for older caregivers from Hamilton and surrounding counties was held at Orange Grove Center in Chattanooga. Older caregivers met Project partners and each other and discussed issues they face in caring for their family member. Some people were providing care for a son or daughter, a sibling, or a spouse. For most, it was the first time ever to meet someone in a similar circumstance.

A follow-up event took place on October 22. Shawn Kurrelmeier, executive director of the Chattanooga Center for Non-Profit Management, facilitated a focus group that gathered comments from caregivers on issues that confront them. Participants shared common experiences, fears, and frustrations. Many were gratified to know that they are not alone in their role as an older caregiver. Some found friends who they plan to see again.

The information gathered at both events will be used to develop materials and resources to support older caregivers in their homes and

communities. A mentor pilot project will link older caregivers with other caregivers of family members with disabilities. The mentors will assist older caregivers to locate supports in the community and to plan for the time when the older caregiver is no longer able to continue in this role.

While limited to Hamilton and surrounding counties, the goal is to develop models that can be used in Tennessee and in other states. Partners in the endeavor include Team Evaluation, the Area Agency on Aging and Disability, the Arc of Hamilton County, Orange Grove Center, Signal Centers, the Tennessee Commission on Aging and Disability, the Tennessee Disability Information and Referral Office at the John F. Kennedy Center of Vanderbilt University, and the Tennessee Council on Developmental Disabilities. This network meets regularly to plan, implement, and evaluate all aspects of the Project.

The Council on Developmental Disabilities was one of only two recipients selected from throughout the nation to receive a two-year federal grant to conduct the pilot project. The other site is the New Hampshire Department of Mental Retardation and Developmental Disabilities. ■

For more information contact:
June Phillips, Team Evaluation
Phone: (423) 622-0500 or
Wanda Willis, Tennessee Council
on Developmental Disabilities
Phone: (615) 532-6615

*Wanda Willis is
 executive director
 of the Tennessee
 Council on
 Developmental
 Disabilities.*

A group of education stakeholders gather to brainstorm at a recent DCE meeting at The Arc of Tennessee.



DCE Sets Goals and Priorities for Coming Year

By Ned Andrew Solomon

The Disability Coalition on Education (DCE) is on a roll. It has a brand new newsletter, an ever-expanding membership, and an informative traveling Forum coming to a town near you. With a new set of goals and priorities for the 2002-03 year, and committee heads and workgroups to spearhead those initiatives, DCE is poised to make positive changes in the quality of school life for kids with and without disabilities across Tennessee.

A statewide alliance, DCE comprises family members, educators, advocacy organizations, and State agencies. The group strives to create partnerships among families, schools, and communities to ensure that all students receive quality education, and that rules, regulations, policies, and practices provide for equal opportunities for all children.

DCE believes

- All students have strengths and talents, and deserve to be respected and valued.
- All students can learn and succeed.
- Students are more successful when families and educators work together.

- All students must have the opportunity to be involved in every dimension of their school experience.
- Students' learning opportunities are diminished when they are segregated.
- Each school system must provide supports to meet the individual needs of all students.

How DCE works. DCE has monthly meetings in Nashville, which are open to anyone who has an interest or stake in issues related to the education of Tennessee's children. DCE also maintains an e-mail list to keep active members and other interested parties aware of educational concerns and happenings throughout the state. DCE is primarily a vehicle for disseminating information, and in some cases taking action through letter writing and meeting with legislators, State Board of Education members, and other stakeholders and policymakers in the area of education.

Goals 2002-2003. Each year, through an extensive brainstorming process acknowledging and respecting input from all members, DCE

selects priority areas and goals, and develops an action plan to implement them. It was decided that in the year 2002-03, DCE should focus on:

- **Creating a culture in Tennessee that supports positive outcomes for all students, including students with disabilities**, by changing the mechanisms and understanding of how students with disabilities are educated in Tennessee schools. Goals include advocating for special education funding, class size, reauthorization of IDEA, and personnel development to State and federal officials. DCE also will collaborate with the Tennessee Education Association in "conversations" with local school officials across the state regarding local efforts to educate students with disabilities using current research and "best practices."
- **Expanding the voice of, and support for, parents of children with disabilities** by increasing the presence and influence of DCE across the state. The group will publish a newsletter, expand its e-mail list, and set up a web page. It will seek to tie together local parent education initiatives through The Arc of Tennessee's LINK project. DCE forums across the state will encourage parent participation in local and State policy-making.
- **Developing a statewide media campaign** whose goal is better public understanding of issues related to educating students with disabilities, and the mission and activities of DCE.
- **Improving the internal operation of DCE** by setting annual goals and strategies aimed at expanding membership and enhancing participation at monthly meetings from members in remote locations.

Taking part.
There is no cost to join DCE. If you or someone you know is interested in joining DCE,

DCE
is poised to make
positive changes in the
quality of school life for kids
with and without disabilities
across Tennessee.

please send your contact information, including phone number, mailing address and e-mail address (if applicable) to: Mark Sloniker at The Arc of Davidson County (mstoniker@arcadc.org), 111 N. Wilson Blvd., Nashville, Tennessee 37205.

There are many possible levels of participation but absolutely no obligation ever to do anything. You may choose only to receive updates from DCE about educational initiatives that we believe are important to any family with a school-aged student, with or without disabilities. If you want to do more—and we encourage you to take the DCE vision as far as you can—here are some of the ways you can help:

- Share the DCE information you receive by e-mail with other folks who are not DCE members, but who might be interested in keeping abreast of educational happenings.
- Help disseminate DCE information to families in your area who may not have access to e-mail.
- Provide comments to DCE regarding educational issues of importance in your area of the state.
- Attend DCE meetings (in person or by phone).
- Join or organize a DCE subcommittee or task force.
- Coordinate local DCE forums.
- Provide educational training opportunities for families in your area.
- Participate in education advocacy activities, such as letter writing or contacting education policymakers.

Want to learn more? Current initiatives, minutes from recent meetings, a downloadable brochure, and links to other important educational and disability-related resources can be found at the Special Education Action Network (SPAN-TN) website at www.SPAN-TN.org. ■

*Ned Andrew
Solomon is director
of the Partners
in Policymaking™
Leadership Institute
at the Tennessee
Council on
Developmental
Disabilities.*

The Arc Recognizes Excellence in Direct Support

By Jim Summerville

“You can do it!” That’s the favorite phrase of **Jennifer McMannis**. A single mother of a 10-year-old son, she has chosen to be live-in companion for two women who receive residential services from Sunrise Communities of Tennessee. The four make their home in Clarksville.

Ms. McMannis emphasizes that it’s not a job—it’s a home. Darlene and Becky moved out of a group setting to find a family experience. Ms. McMannis and her son have formed such a circle for and with them. She assists the women in expanding their daily personal care skills and taking on their share of the responsibilities of homemaking. With her slogan that insists that they know how, she spurs them to make their beds, set the table at mealtimes, and load the dishwasher.

Darlene and Becky returned the favor recently. They were on hand to cheer Ms. McMannis when she received one of this year’s Direct Support Professional Awards from The Arc of Tennessee at its annual convention.

The Arc awards program recognizes excellence in providing direct supports to people with mental retardation and related disabilities. Those honored have supported individuals to live in and be part of the community and helped them to make and implement responsible choices about what is important in their lives.

Eleven other recipients joined Ms. McMannis on the platform to receive a 2002 Direct Support Professional Award.

Lynette West, of Homeplace, Inc., has provided principal support to four women since 1996, helping

each one to become independent and responsible. According to her ability and interest, each of these individuals has taken on a certain area of housekeeping.

For his friendship, guidance, and service as a role model, **Michael Lowery** of Hilltoppers, Inc., received The Arc’s prestigious recognition. For 22 years, Mr. Lowery has, in the words of the citation, “demonstrated personal initiative in the identification of consumer needs and developed strategies to provide the needed supports.”

Daphne Hodges currently helps some 35 people keep appointments with their physicians. Ms. Hodges works at Greene County Skills, Inc., Greeneville. Above and beyond that call of duty, she takes individuals on outings, offering them choices about what they would like to do.

At Progressive Directions, **Nicole Sanders** has been supporting individuals since 1989, the year she turned 18. According to Montgomery County Arc president Joanne Wilson, Ms. Sanders has been an “important friend and confidante to dozens of consumers . . . I know she has been disappointed, angered, hit, spit on, underpaid, overworked, and under-appreciated—yet she stayed.”

“Ms. Harriett” moved from Arlington Developmental Center in the spring of 1998 to a home of her own in Camden. She requires extensive care, including G-tube feedings and respirator monitoring. Providing this sustaining care is **Sandra Doss**, a licensed practical nurse and full-time direct support professional. The Arc Award noted how Ms. Doss provides “loving, pampering, spoiling, nurturing, entertaining, securing, humoring, indulging, and caring supports.”

Don Haughton, who works for Mid-TN Supported Living, has served as a live-in companion for Terry. When they met, Terry had



She’s a winner, too! Elaine Washington of Developmental Services of Dickson proudly displays her Arc award.

Those
honored have supported individuals to live
in and be part of the community and helped them to make
and implement responsible
choices about what is
important in their
lives.

challenging behaviors, such as shouting when he wanted something but was otherwise withdrawn.

Mr. Haughton has shown his young friend how to ask, "What are my choices?"

Terry recently became a homeowner through Don's assistance.

Walter Ligon, Jr., an employee of The STAR Center, Jackson, has served as a personal assistant with the same individual for eight years. This consumer is able to live in his own home, take part in community events, and maintain relationships with his family.

Michael, a citizen of Greene County, lived in institutions for 20 years. In early 2001, he moved into a home of his own in Greeneville, supported by **Twana Summie** of Sunrise Communities of Tennessee. Michael loves being around emergency service personnel, and Twana has helped him become an honorary

member of the local fire department. With her support on the job, he also works at the Greene County Bank.

For more than seven years, **Elaine Washington**, with Developmental Services of Dickson, has provided one-to-one support and care for Alex, a young man who lives with his parents, Dara and David Howe. According to The Arc citation for her award, "Ms. Washington is always at Alex's side, taking care of his personal needs with tenderness, talking to him, reading to him, playing games with him, and entertaining him in his stander." Says Ms. Howe: "When you look up 'saint' in the dictionary, you should find Elaine's picture." ■

For more information contact:

Arc of Tennessee

**44 Vantage Way, 5th Floor
Suite 550**

Nashville, TN 37228

Phone: (615) 248-5878

Fax: (615) 248-5879

E-mail: wrogers@thearctn.org

Website: www.thearctn.org

Jim Summerville

is editor of

Breaking Ground.

Pictured left to right

Top row:

**Nicole Saunders,
Don Haughton,
Michael Lowery,
Wylie Ligon, Jr.,
Leanne
Chamberlain,
Sandra Doss**

Bottom row:

**Jennifer McMannis,
Twana Summie,
Daphne Hodges,
Anita Pritchett,
Lyn West**





Information Office Reaches Out to Tennesseans of Latino Heritage

By Solange Bishop

Hello everyone! I have had a busy and productive eight months since I started my position here at the Tennessee Disability Information and Referral Office (TDIR). I began by learning about the disability-related resources in the state, acquiring an understanding of the laws that affect the quality of life of individuals with disabilities, and using all this information to make quality referrals to our callers.

During this time, I have assisted a significant number of people. The calls are brief when the individual needs specific information, such as the number of an agency that can assist with a problem. Many times the process gets involved, requiring me to make several calls to ensure that the individual is provided with accurate information and the appropriate referral. As we talk together, I learn about the individuals, as they relate their hopes, concerns, and the daily struggles they encounter in their repeated attempts to receive much needed assistance. I am honored to be their confidante.

In June 2002, I began concerted efforts to provide outreach to the Hispanic/Latino community. The TDIR sent brochures and bilingual flyers regarding its programs to many agencies, hospitals, and clinics throughout the state. This will be an ongoing effort to inform individuals and agencies of the services of TDIR. I also participated as a panelist in two Hispanic/Latino forums. More recently, I have served as a facilitator for Spanish-speaking individuals assisting them to

connect with the appropriate service providers over the telephone or face-to-face.

Identifying Hispanic/Latino resources in local communities that may assist families is an ongoing goal. In my search for resources for nonprofit agencies that provide services to the Hispanic/Latino and Limited English Proficiency population, I began by identifying agencies that provide bilingual staff. This is sometimes vital information to have before I can make appropriate referrals. I have tried, therefore, to develop an understanding of the federal anti-discrimination laws to identify which agencies are required to provide interpreter services to eligible recipients.

Title VI of the Civil Rights Act of 1964 decrees "No person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." This raises several pertinent questions:

What qualifies as federal financial assistance?

Federal financial assistance includes, but is not limited to, grants and loans of federal funds; loan of federal personnel; federal training; use of equipment; donations of surplus property; and other assistance.

Who are the recipients of federal financial assistance?

Institutions or programs that may receive funds are the following:

Information & Referral Office

11

- Extended care facilities
- Public assistance programs
- Nursing homes
- Adoption agencies
- Hospitals
- Day care centers
- Mental health centers
- Senior citizen centers
- Medicaid and Medicare
- Family health centers and clinics
- Alcohol and drug treatment centers
- School districts
- Police departments
- Foster care homes
- Nutrition programs
- Physicians and other health care professionals in private practice with patients assisted by Medicaid

Who is considered to have limited English proficiency?

Individuals who do not speak English as their primary language and have a limited ability to read, write, speak, or understand English are considered to have limited English proficiency.

Most importantly, what is discrimination on the basis of national origin?

Discrimination means delaying or denying services because the service provider cannot communicate with such individuals; giving different services to people who do not speak English, segregating, or separately treating individuals in any matter related to their service, aid or benefit. To ensure equal access to benefits for persons with Limited English Proficiency (LEP), the service provider and the LEP persons must communicate effectively. Agencies must provide interpreters who are appropriately trained and who can accurately translate, either in person or by telephone. Agencies must offer a translated explanation of

the person's rights and any forms that must be signed by applicants for services. Agencies must not require persons seeking services to provide their own interpreters. ■

For information on how to file a complaint of discrimination or to obtain information of a civil rights matter please contact:

Tennessee Protection and Advocacy, Inc.

Phone: 1-800-342-1660 or the

Office for Civil Rights (OCR)

Voice: 1-800-368-1019

TTY: 1-800-537-7697

E-mail: ocrmail@hhs.gov

Website: www.hhs.gov/ocr

The Tennessee Disability Information & Referral Office is "a good place to start" when seeking current disability information and support services around the state. The scope of information includes all disabilities and individuals of all ages. Service is provided in English and Spanish.

Searching for resources and facilitating access to those resources is an important ongoing process. If you have questions or concerns, please contact the Tennessee Disability Information and Referral Office.

English & Spanish: 1-800-640-4636

TDD: 1-800-273-9595

Voice/Nashville: (615) 322-8529

Voice/Español: (615) 322-7830

E-mail: solange.bishop@vanderbilt.edu

or carol.moore-slater@vanderbilt.edu

Website: www.familypathfinder.org

Solange Bishop, bilingual information specialist, has been with the Tennessee Disability Information & Referral Office since February 2002.

Fourteen Join Council Ranks

By Errol Elshtain

In September, Governor Don Sundquist named several new members to the Council on Developmental Disabilities. In future issues of *Breaking Ground*, we will introduce you to each new member individually. These new members received an orientation to the Council at the beginning of October.

The Governor also, upon the recommendation of the Council, appointed new officers: **Andrea L. Cooper**, Chair, and **Joyce Elaine Sievers**, Vice-Chair.

Reappointed to serve a second term on the Council were: **Randy Oliver** from Jackson and **June Mangum** from Memphis.

In addition to the community members of the Council, the Governor acted on the recommendation that two new agencies be included on the Council: Bureau of TennCare and Tennessee Housing Development Agency (THDA).

Joanna Damons, Director of Long-Term Care, will represent the Bureau of TennCare. **Janice Myrick**, Executive Director, will represent THDA. **Gregory Yopp**, Director of Children's Special Services, Division of Maternal and Child Health, Department of Health, replaces

New Community Council Members:

Janet Anderson, Fayetteville
David Duncan, Dyersburg
Marti Finch, Bristol
Barron A. Garrett, McMinnville
Coral Getino, Knoxville
Mary Dale Greene, Columbia
Nancy Hardin, Dyersburg
Richard Moore, J.D., Brentwood
Marilyn (Diana) Seavey, Cleveland
Steve Sheegog, Memphis
Rebecca Smith, McMinnville
Kenneth Tedford, Johnson City

Suzanne Rothacker, who recently retired.

The Council was happy to welcome its newest members but sad to say goodbye to several whose terms had ended. These retiring members, who gave generously of their time and experience, are

Steve Bowland, Crossville
 Mollie Richardson, Lynnville
 Brandi Barfield-White, Columbia
 Joseph M. Evangelisti, Memphis
 Debbie Bonner, Sewanee

Ms. Bonner, an at-large member who also had served as vice-chair of the Council, and Mr. Bowland attended the retreat and received tokens of appreciation for their service to the Council (see page 14). ■

Errol Elshtain is planning coordinator at the Tennessee Council on Developmental Disabilities.

Nine of the fourteen new Council members.



Gathering Ideas for the Future

By Errol Elshtain

Despite the rains of Hurricane Lily and a local power outage, the Tennessee Council on Developmental Disabilities completed a successful annual retreat at the beginning of October at Montgomery Bell State Park. With the recent appointment of twelve new consumer members and two new State agency members, this event was coupled with an orientation to the Council. We will be introducing the new Council members to our readers in future issues of *Breaking Ground*.

There were substantial accomplishments to review for fiscal year 2001-2002. Numerous Council activities and grants led to significant achievements during the year. Council members also heard about new initiatives and the plans of continuing projects. Following this presentation, there was lively discussion about how much the Council does, the amount of research involved before projects are undertaken, and the increasing focus on self-determination. Cited among these exemplary projects were the Microboards, Tennessee Disability Voters, Tennessee Disability Information and Referral Office (TDIR), Partners in Policymaking™ Leadership Institute, and the Homeownership Project.

In order to think about what the Council agenda might be for the coming year, members looked at current trends and topics in the disability community.

Education

Michael L. Remus, director of special education in Williamson County, spoke to the group about education activities on the federal and State levels. He predicted that several federal issues will have special impact in coming days.

- There will be long-term effects as a result of the new federal initiative, "No Child Left Behind." The key term is accountability. Teachers will have to be qualified to teach students receiving special education. Similarly,

educational assistants (teachers' aides) will have to have at least a two-year college degree or qualify by means of a test or assessment tool.

- A big item at the federal level is the reauthorization of the Individuals with Disabilities Education Act (IDEA). Already, many hearings have been held across the country so that Congress could hear about what is and what is not working with IDEA. A major issue centers on discipline, as was true during the last reauthorization. The critical aspect here is to retain the concept that students with disabilities must continue to receive services regardless of the disciplinary action taken. A controversial point in the discipline debate concerns the definition of a behavior that is disruptive.
- Other areas under discussion are a reduction in paperwork and the progress of students with disabilities. For the former, a three-year Individual Education Plan (IEP) is being considered. For the latter, another accountability issue, the question is how to know whether students with disabilities are progressing in school and how to develop data to measure their progress.

Turning to Tennessee, Mr. Remus described the new eligibility requirements for special education. Currently, these requirements are serving in a gatekeeping capacity. For example, children with learning disabilities or those requiring speech therapy may not qualify for special education in the future.

Whereas the State once used monitoring visits to schools, Mr. Remus continued, Tennessee has moved to self-assessments to find out how school districts are doing. This is a multi-year process in which the school district looks at what they are doing well and where they are falling short. The process is family-oriented with a steering committee on which community and family members serve.

continued on the next page

Class size or caseload is a current item of discussion in Tennessee. Mr. Remus said the ideal is to set up a class to be successful. Many times, children in special education have just been grouped together. In Williamson County, they are looking at this issue by means of a matrix and formula to determine how many children should be in a classroom in order to maximize the potential for their success in school.

On the local level, Mr. Remus told the Council, Middle Tennessee special education directors have been meeting to address several areas:

- How to obtain and retain staff
- Mentoring for self-assessment
- "No Child Left Behind"
- The lack of State and local communication
- The need for more technical assistance
- Gifted education—where should it be?
- Children with behavior issues

In summary, Mr. Remus noted that, "little by little," things are happening to improve special education in Tennessee.

Tennessee Olmstead Coalition

The activities and history of the Tennessee Olmstead Coalition (TOC) were reviewed by means of a video segment from the Council-supported *Journeys...Redefining*

Ability television show. The TOC takes its name from the 1999 Supreme Court *Olmstead v. L.C.* decision which interpreted Title II of the Americans with Disabilities Act (ADA) as requiring states to administer their services, programs, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." Following this decision, both the Clinton and Bush administrations encouraged states to develop comprehensive plans to ensure that individuals with disabilities receive services in the most integrated setting appropriate to their needs.

The Tennessee Olmstead Coalition was established to begin the groundwork for a plan for Tennessee. The video described this activity and gave examples of individuals currently living in nursing homes who could, with some support, live active lives in the community.

Other Issues

The Council heard about other issues affecting people with disabilities. Awaiting Phil Bredezen and his Cabinet will be TennCare, the State budget, the capacity of agencies to provide home and community-based services, the continuing effects of litigation against the State (the Arlington Remedial Order, the Clover Bottom Settlement Agreement, the Waiting List suit), and the status of various State Medicaid waivers.



Outgoing Council members Debbie Bonner, left, and Steve Bowland, right, receive a certificate of appreciation for their years of service from executive director Wanda Willis.



Retreat to advance: Council members settle on priorities for the next year.

Armed with information from the morning and afternoon presentations, Council members divided into small groups to identify strategic questions about Council programs and initiatives. The full group then reconvened to identify Council priorities. The general areas included health care, education, transportation, promoting self-determination, social opportunities, support for direct support personnel, employment, ADA, elderly caregiver services, promoting best practices, interagency networking, and the continuation of programs after Council funding has ended.

To bring together the information from the first day of the retreat, Council members worked in pairs to reach agreement about how to invest a hypothetical “windfall gift” of \$1 million per year for three years in one high-priority initiative. The responses were:

- Invest in home- and community-based support for housing, employment, and health care, emphasizing direct financial support.
- Provide support for individuals to live independently in a setting of their choice with employment and social activities.
- Develop more supports for older caregivers by expanding the Chattanooga model and including peer counseling. (For a description of the Chattanooga model, see page 5.)
- Expand the Microboard Program, especially training for individuals, caregivers and supporters, and access to housing.
- Start a public education campaign focusing on the person (not the State) as the customer and provide direct financial assistance to the person to spend as needed.

- Develop transportation alternatives, such as privatization or community groups as providers; develop a computer database to coordinate public and private resources to respond to transportation customer requests.
- Improve health care services by reaching out to professionals and linking with medical associations.
- Add to the web site at the Tennessee Disability Information and Referral Office.
- Partner with YMCAs, YWCAs, and other community groups.

Finally, in the midst of a power outage, four groups used an evaluation guideline to review the Council’s current mission statement. While the groups agreed that the mission statement was adequate, they also felt it lacked a certain inspirational tone (“pizzazz” was the word used) and did not refer to self-determination. A small task force is taking the comments and will prepare a new version of the mission statement for Council review.

Despite listening and working hard, the Council left the day-and-a-half retreat energized and looking forward to developing new initiatives across Tennessee. Each member and staff took away a positive outlook toward achieving the Council’s vision:

People with disabilities are fully included in the community and experience no barriers related to attitudes about their disability as they pursue their goals in education, housing, employment and all other activities of daily living. ■

Don Meyer and Theda Wiles Zawaiza to Headline Partners 9th Annual Reunion

By Ned Andrew Solomon



The tenth season of Tennessee Partners in Policymaking™ Leadership Institute is underway and going strong, with individuals with disabilities and family members from across the state honing their skills to become more effective advocates in their communities. The current Partners will have a great chance to meet and network with Partners grads from years past at the upcoming 9th Annual Partners Reunion Conference in downtown Nashville, February 7 & 8, 2003.

Although the agenda is far from complete, the keynoter and federal legislative update presenter have been selected. Don Meyer will start the proceedings on Friday afternoon with his address, "Sibs, Dads, and Grandparents: Too Important to Ignore." Those fortunate enough to hear Mr. Meyer's session last year on the role of siblings in the lives of individuals with disabilities know that his message is eye, ear, and heart opening.

Mr. Meyer is director of the Sibling Support Project at The Arc of the United States. He has conducted more than 200 workshops training some 8,000 parents and providers on sibling issues and the Sibshop model. He was also a founder of the SEFAM (Supporting Extended Family Members) program at the University of Washington, which pioneered services for fathers, siblings, and grandparents of children with special needs. In addition to his keynote address, Mr. Meyer will offer a special workshop for fathers during two of the afternoon breakout sessions.

It has been a tradition at the February reunion to invite a speaker

to give current and graduate Partners a glimpse into disability issues and legislation on a federal level. This year the program is pleased to have Theda Wiles Zawaiza, Ph.D., in that role. Dr. Zawaiza has been involved in the field of disabilities for the past 28 years in various capacities, including 10 years as a special educator in New York and California. She is currently consulting with three federal agencies—the United States Social Security Administration, Office of Employment Support Programs, and the National Council on Disability. In these capacities, she serves as a senior policy advisor on cultural diversity and equity issues in disability policy.

Dr. Zawaiza's experience includes service as special assistant for equity in the Office of the Secretary at the U.S. Department of Education. In the Clinton Administration Dr. Zawaiza was a special assistant to Assistant Secretary Judith E. Heumann, in the Office of Special Education and Rehabilitative Services. Dr. Zawaiza has also been a senior legislative analyst with a Congressional subcommittee on select education and civil rights, where she helped develop and refine federal policy on disability rights and services. ■

For more information please contact:

Ned Andrew Solomon
Director, Partners in Policymaking™
Council on Developmental Disabilities
Andrew Jackson Building
13th Floor, Suite 1310
Nashville, TN 37243-0228
Phone: (615) 532-6556
Fax: (615) 532-6964
TTY: (615) 741-4562
E-mail: ned.solomon@state.tn.us

Ned Andrew Solomon is director of the Partners in Policymaking™ Leadership Institute at the Tennessee Council on Developmental Disabilities.



Youth Leadership Forum 2003

17

The Council on Developmental Disabilities is currently accepting applications for its fourth annual Tennessee Youth Leadership Forum, to be held in June 8-12, 2003, on the Vanderbilt University campus. YLF is designed to provide 10th, 11th, and 12th grade high school students who have disabilities with information about disability issues, and to help them become advocates for themselves and for others in their communities.

Participants attend a four-day conference where they participate in small and large group

discussions, listen to local and national speakers in the field of disabilities, travel to Legislative Plaza to tour the Capitol and meet with legislators, and complete written materials that are designed to augment their self-advocacy and leadership skills.

Each year, a class of 20-30 participants is selected from across Tennessee. Criteria for acceptance stipulate that each participant be a person with a disability, and that potential YLF delegates have an inclination toward leadership in their communities. Room, materials, and travel to and from the Forum

are provided at no cost to participants.■

For further information or an application, please contact:

Ned Andrew Solomon, Director
Partners in Policymaking™
Council on Developmental
Disabilities

Andrew Jackson Building
13th Floor, Suite 1310

Nashville, TN 37243-0228

Phone: (615) 532-6556

Fax: (615) 532-6964

TTY: (615) 741-4562

E-mail:

ned.solomon@state.tn.us

Ms. Getino Honored For Advocacy



2001-02 Partners in Policymaking™ Graduate and new Council member Coral Getino was recognized at the STEP and LRE for Life FAST (Families and Schools Together) conference in Knoxville in mid-October. Ms. Getino received

the Wayne Parker Advocate-of-the-Year Award 2002, presented by STEP to "a parent of a family member whose advocacy efforts have been remarkable on behalf of their child with a disability or an individual with a disability whose self-advocacy

has been extraordinary." The commendation celebrated Ms. Getino's extraordinary efforts to achieve an inclusive setting for her son, Justin, in the Knox County school system. Congratulations Coral!■

VOTE! Campaign Looks Ahead

By Joanne Rich

As citizens we have the right and the responsibility to cast our votes and participate in the governing of our communities. The policies developed and implemented by those we elect have an impact on each of us every day.

The **VOTE!** campaign is designed to give each of us an opportunity to participate in the process. Each contribution, be it of time, talent or ideas, is an important component in making the voting and election processes accessible to all citizens.

The importance of voter participation by people with disabilities should be a part of every communication from your organization, year in and year out. The connection to the community and the value friends and family place on voting are crucial determinants of electoral participation. The greater one's integration into social networks that value voting, the more likely it is that one will vote.

On behalf of the Tennessee Disability Voters and the Tennessee Disability Coalition, we invite you to be part of a non-partisan, statewide campaign to organize the disability community to be an important force in the political and policy process. Together we can:

- Increase the number of people with disabilities and their supporters who are registered and who vote.
- Decrease/eliminate barriers to voting for people with disabilities, including policy barriers, access barriers, and social and practical barriers.
- Establish a network of local, grass-roots **VOTE!** Committees that can work on registration, poll access, get-out-the-vote, issue advocacy, and election campaigns in their own communities.

- Provide broad-based and targeted voter education on both the voting process and disability related issues.

How to get started

The first step is to develop a local steering committee. The members of the steering committee will serve as leaders of **VOTE!** This is your opportunity to invite various community leaders to join you on this project. Broad outreach will help to build working relationships that will better serve the whole community.

Who should serve on this committee?

Along with members of your organization, you may consider asking the County Election Commissioner, the Mayor, the chair from each political party, a member of the League of Women Voters, service providers, members of other civic groups, Chamber of Commerce officers, and industry leaders.

The Steering Committee shapes the strategic plan. Once the committee has been formed, the goals and activities of **VOTE!** will begin to take shape. This starts with an assessment of current community conditions—strengths and weaknesses and an assessment of opportunities. A plan should address the key elements needed to increase voting and civic participation. This means voter registration, education, access, and “Get Out the Vote.”

VOTE! will grow as you feel comfortable. Each community is unique, and you will find the best way to approach your goals. Here are suggestions of activities to get you thinking.

- **Voter registration drives:** Your local election commission can help supply you with all the materials you will need. A voter registration drive can take place in conjunction with another activity, or it can be the main activity. All you need are volunteers, forms, pens, and a table.

*Joanne Rich is
VOTE! project
coordinator at the
Tennessee Disability
Coalition.*

- **Motor Voter implementation:** Service providers and state offices that serve people with disabilities should be registering people to vote. Working with them on successful implementation of the federal law will increase voter registration.
- **Practice voting:** County election commissions can provide voting machines for mock elections or dress rehearsals. This gives people who are voting for the first time an opportunity to learn the process of voting before Election Day. Your election commissions may be willing to provide machines for organizations to hold elections for their officers. This is another opportunity to practice using voting equipment. Real political candidate's names cannot be used in practice sessions.
- **Conduct disability awareness activities:** Engaging in awareness activities or disability sensitivity training for election officials and officers (poll workers) are ways to improve the voting experience for people with disabilities. Many election officials or officers have had no experience working with people with disabilities. Don't forget to sign up as an election officer for the commission. This is an excellent way to serve your committee.
- **Phone banks:** There are many useful ways to utilize the phone bank system. Call and remind people to vote. Remind them of dates of early voting, times the polls are open and which are accessible. Keep a list of the persons you have registered and those you know who care about disability issues.

- **Invite elected officials to speak to your organization:** Use this time as an opportunity to educate and be educated. Share your concerns and offer to supply information to elected officials. Offer your assistance.
- **Poll accessibility:** Contact your local election commission and offer to help with locating accessible polling places or provide technical assistance on accessibility. Educate the commission on accessible equipment.
- **Candidate forums:** Setting up your own forums, panel discussions, or "town hall meetings," or organizing attendance at other forums are good ways to raise awareness, to provide education, and to learn about issues and candidates. There are many tools available to help you organize your own forum. To raise disability-related issues in other forums, watch for notices and inform others. Do your homework. If the forum is designed to deal with one topic, understand that the candidates may not feel comfortable addressing other issues. On the other hand, an open question and answer session may be provided during which you can ask a question on any issue.
- **Transportation:** Offering transportation to those who need it and assistance at the polls is a vital part of getting out the vote. A mailer could be sent out reminding citizens of voting dates, times, and locations, noting locations not accessible. Include on the postcard a number that can be called where assistance can be obtained for voting and transportation. ■

Editor: Mr. Jim Summerville
Contributing Editor: Dr. Jan Rosemergy
Graphic Design: Ms. Kylie Beck

About the Council:

The Tennessee Council on Developmental Disabilities provides leadership to ensure independence, productivity, integration, and inclusion of individuals with disabilities in the community through promotion of systems change.

The editor will consider for publication original contributions, including news and feature stories, short fiction, poetry, artwork, and photographs but reserves the right to edit or decline publication. Brief letters to the editor are also welcome. Opinions expressed in any published matter are the author's and not necessarily those of the Tennessee Council on Developmental Disabilities or its staff.

This free publication is produced six times a year by the John F. Kennedy Center for Research on Human Development at Vanderbilt University. Subscription requests, change of address, and submissions for possible publication should be directed to the Editor, *Breaking Ground*, Vanderbilt University, Peabody Box 40, Nashville, Tennessee 37203. Telephone (615) 322-8473 or 1-800-288-0403; TDD (615) 343-3330 or 1-800-288-3311; FAX (615) 322-8236. E-mail: Jim.Summerville@Vanderbilt.edu

Tennessee Department of Mental Health and Developmental Disabilities, Tennessee Council on Developmental Disabilities Grant Number 1-03999-1-0. Authorization Number 339371, July 2001. 5,600 copies. This public document was promulgated at a cost of \$.46 per copy.



Applications for Youth Leadership Forum (YLF) available! See page 17

MEMBERSHIP & STAFF

Council Chairpersons

Andrea L. Cooper, *Chair*

Joyce Sievers, *Vice Chair*

Council Members

Janet Anderson, *Fayetteville*

David Duncan, *Dyersburg*

Sara Ezell, *Nashville*

Marti Finch, *Bristol*

Barron A. Garrett, *McMinnville*

Coral Getino, *Knoxville*

Mary Dale Greene, *Columbia*

Nancy Hardin, *Dyersburg*

Richard Johnson, *Bartlett*

June Mangum, *Memphis*

Richard Moore, J.D., *Brentwood*

Alan Muir, *Knoxville*

Randy Oliver, *Jackson*

Linda Poole, *Jackson*

Marilyn (Diana) Seavey, *Cleveland*

Steven Sheegog, *Memphis*

Rebecca Smith, *McMinnville*

Kenneth Tedford, *Johnson City*

State Agency Representatives

Carl Brown

Department of Human Services,

Division of Vocational Rehabilitation

Joanna Damons

Bureau of TennCare

Joseph E. Fisher

Department of Education,

Division of Special Education

Richard Kellogg

Department of Finance and Administration,

Division of Mental Retardation Services

Janice Myrick

Tennessee Housing Development Agency

Elisabeth Rukeyser

Department of Mental Health and

Developmental Disabilities

Patricia Wade

Commission on Children and Youth

James S. Whaley

Commission on Aging and Disability

Gregory Yopp

Department of Health,

Children's Special Services

University Center for Excellence Representative

Frederick Palmer

UT Center for Health Services

Protection & Advocacy

Shirley Shea

Tennessee Protection and Advocacy

Council Staff

Wanda Willis, *Executive Director*

Errol Elshtain, *Planning Coordinator*

Rita L. Carter, *Administrative Asst.*

Margaret Donald, *Administrative Sec.*

Alicia A. Cone, *Policy Analyst*

Lynette Swinford, *Fiscal Manager*

Ned Solomon, *Director, Partners*

in Policymaking Leadership Institute

For more information about the Council, contact the Council office at the Andrew Jackson Building

500 Deaderick Street, 13th floor, Suite 1310, Nashville, TN 37243-0228

Telephone (615) 532-6615 • TTY (615) 741-4562 • Fax (615) 532-6964

E-mail tnddc@state.tn.us • Web site www.state.tn.us/cdd

Vanderbilt University
John F. Kennedy Center
Peabody Box 40
230 Appleton Place
Nashville, TN 37203-5701

Return Service Requested

Nonprofit Org.
U.S. Postage

PAID

Nashville, TN
Permit No. 1460